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Authors

Cedars, Benjamin E
Cohen, Andrew J
Fergus, Kirkpatrick B
et al.

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Qualitative Analysis of the Content Found in Online Discussion Boards for Urethral Stricture Disease and Urethroplasty

Benjamin E. Cedars, Andrew J. Cohen, Kirkpatrick B. Fergus, Nima Baradaran, Medina Ndoye, Puneet Kamal, and Benjamin N. Breyer

OBJECTIVE To describe the patient experience and chief concerns with urethroplasty to improve physician understanding and patient education. Online discussion boards allow patients with urethral stricture disease (USD) to connect with other USD patients. It is unknown how men use these web resources and what information is available about urethroplasty.

METHODS Three online forums featuring urethroplasty were identified by Google search. Thematic analysis categorized the content of posts using manually applied codes, with inter-rater reliability and descriptive statistics generated by Dedoose (Los Angeles, CA).

RESULTS A total of 140 unique posters contributed 553 posts to the forums. Posts were categorized as information support (n = 651), issues posturethroplasty (n = 470), own experience preurethroplasty (n = 336), feelings towards other posters (n = 312), what to expect posturethroplasty (n = 265), feelings after urethroplasty (n = 228), and considerations before urethroplasty (n = 134). Experience navigating the healthcare system with USD (n = 141) and weak urine stream (n = 70) were the most frequent preurethroplasty complaints. Postoperative pain (n = 164) was the most frequent issue. Patients expressed more positivity (n = 126) and satisfaction (n = 120) than negativity (n = 33) with urethroplasty.

CONCLUSION Patients participated in online discussions to share experiences with USD and urethroplasty, receive emotional support, and find answers. Men were more often satisfied than not with their urethroplasty outcomes, with 88% of postoperative feelings coded as positive or satisfied compared to negative. This study provides physicians with insight into the experiences of patients and how to best educate them. UROLOGY 130: 155–161, 2019. © 2019 Elsevier Inc.

Support groups are an effective method through which patients may seek emotional, informational, or social encouragement while facing medical problems.[1] With the advent of the internet, it has become increasingly common for individuals to find and support each other virtually. According to the Pew Research Center, 72% of adult internet users have searched for health information online within the past year, and 16% have sought others who share their health concerns or problems.[2] In prior qualitative analyses of online health forums for patients with chronic cough, breast and prostate cancer, and vasectomy, researchers concluded that the online community generally provided patients with beneficial support and information.[3-6] Genitourinary disease is especially suitable for online interaction, given that relative anonymity may reduce any potential embarrassment when discussing sensitive issues.

One such disease that may benefit is urethral stricture disease (USD), which negatively influences many facets of men's health and quality of life. It accounts for 1.5 million office visits per year in the US and is associated with considerable symptom burden and cost.[7] By describing the quantity and quality of online discussions, providers may better educate patients about their disease or expectations regarding treatment success. Indeed, patients and physicians do not always define urethroplasty's success the same way and may have differing priorities.[8] Understanding the patient's perspectives and goals fosters shared-decision making, a major tenet of improving the quality of care.[3]

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From the Sidney Kimmel Medical College at Thomas Jefferson University, Philadelphia, PA; the Department of Urology, University of California San Francisco, San Francisco, CA; the Department of Urology, Ohio State University Wexner Medical Center, Columbus, OH; and the Department of Biostatistics and Epidemiology, University of California San Francisco, San Francisco, CA

Address correspondence to: Benjamin Breyer, M.D., University of California San Francisco, 1001 Potrero Ave, Suite 3A20, San Francisco, CA 94110-1444.

E-mail: benjamin.breyer@ucsf.edu

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There is a paucity of literature about online forums' impact on patient understanding, attitudes, and decision-making regarding USD. Our objective is to systematically describe the patient experience of those suffering from USD, as viewed through the lens of their online health forum activity. In gaining further understanding of common patient concerns surrounding USD, we ultimately can improve patient education, counseling, quality of care, and patient satisfaction.

MATERIALS AND METHODS

Forum Selection

Online discussion boards were identified with an internet search using the term "urethroplasty discussion forum." Three forums met these inclusion criteria: livingwithacatheter.com (https://livingwithacatheter.com/stories-from-others-who-have-had-urethroplasty/, accessed 19 May 2018), patient.info (https://patient.info/forums/discuss/i-have-urethra-stricture-need-some-suggestion-for-the-details-below−545038, accessed 19 May 2018), and medhelp.org (https://www.medhelp.org/posts/Urology/Recently-had-a-Urethroplasty-done/show/1680722, accessed 19 May 2018). Supplementary Figure 1 displays the process of selecting discussion boards from the 3 websites. Initially, 540 discussion boards were identified. Discussion boards were first excluded if there were less than or equal to 10 posts, if the topic was not regarding USD, or they were outside our time criteria of January 2012-May 2018. Excluded topics included urethrotomy, self-dilation, suprapubic catheters, and female USD. Any individual poster who accounted for more than 25% of the posts within a forum was excluded to ensure that 1 individual did not bias our results.

Post Eligibility

Only posts from January 2012-May 2018 were included in our analysis. Eligible posts were written by the patient or by family members (3 spouses, 1 mother, and 1 son). Posts by the moderator of one of the forums were excluded because his contributions represented 36% of posts. One woman with a urethral stricture was excluded, as was a man diagnosed with prostatitis. Unique usernames that were determined to be the same individual—based on similar usernames (eg, John Smith and John S.), timing of posts, and pertinent details—were combined and coded as 1 person.

Coding Process

Thematic codes were created based on the first 10% of posts in each board, utilizing principles of grounded theory.[4] Open codes were created based on specific content of sentences or paragraphs, such as problems related to the disease or patients' emotions and experiences. Axial codes then established connections between and consolidated open codes. For example, various open codes about having a catheter after urethroplasty—general discomfort, catheter-associated pain with urination or erections, and logistics of wearing a catheter bag—were combined into catheter-related issues. Finally, selective codes unified axial codes into broad categories, such as issues posturethroplasty or information support. Figure 1 lists the 49 selective and axial codes and their frequencies. Selective codes were applied to any application of their axial codes. If an excerpt contained information that did not have a matching code, then the relevant selective code was applied individually. Positivity was applied for positive emotions "happy," "excited," etc. Satisfaction was applied for statements of satisfaction related to urethroplasty. Negativity was attributed to feelings related to dissatisfaction, unhappiness, and being upset about results or problems. Multiple codes could be applied per excerpt, so if a patient expressed both positivity and satisfaction within the same excerpt, they would both be applied along with the appropriate selective code. Therefore, axial codes may sum to more than the total counts of selective codes. Supplementary Figure 2 provides definitions for all of the selective codes created for the study.

Analysis

The qualitative analysis program Dedoose (Los Angeles, CA. v8.0.35, 2018) was used to apply codes to excerpts and to analyze them using descriptive statistics. Three researchers applied codes to the forum posts. We gauged coding agreement by having the researchers apply codes to the same posts and comparing for reliability. Dedoose provides a function for comparing inter-rater reliability using Cohen's kappa coefficient. Codes with kappa coefficient corresponding to moderate or greater agreement were considered sufficient, while those that were fair or worse were openly discussed and unanimously agreed upon, then recoded to ensure consistent code application.

RESULTS

There were 140 unique posters to the forums with 553 total posts and 5137 code applications. Of the men posting, 93 (66%) had undergone urethroplasty, 44 (31%) had not, and 3 (2%) could not be determined (Supplementary Fig. 3). By procedure, 42 (45%) underwent buccal mucosal graft (BMG), 18 (19%) had end-to-end anastomosis, 1 (1%) had a lingual graft, and 32 (34%) were unspecified. Three men were undergoing a second urethroplasty, and 4 had completed the first of a 2-stage procedure. Time from operation to first post in an online forum demonstrated the following breakdown: 47 (51%) posted after less than 1 month, 31 (33%) posted from 1 to 6 months postoperatively, 2 (2%) posted after greater than 6 months to 1 year, 4 (4%) posted after greater than 1 year, and 9 (10%) did not specify (though 7 of these men used words indicating their operations were recent). Figure 1 shows the total frequencies for each code. The most common themes were information support (n = 651), issues posturethroplasty (n = 470), and own experience preurethroplasty (n = 336). There was a strong, consistent sentiment in forums that medical questions and issues should be directed towards a urologist or other physician.

Navigating the healthcare system (n = 141) was the most frequent experience preurethroplasty. The next most common preurethroplasty topics were stricture details (n = 100), urine stream (n = 70), emotional distress (n = 50), catheter-related (n = 37), and pain (n = 36). Healing process (n = 123) was the most common subject for what to expect, then operation details (n = 68) and catheter-related (n = 52). Under considerations before urethroplasty, posters were most interested in questions about recovery (n = 61), then feelings about urethroplasty (n = 53) and questions about the operation (n = 36). The biggest issue posturethroplasty was pain (n = 164), followed by catheter-related (n = 85), voiding problem (n = 71), and erections (n = 62). Positivity (n = 126, by 44% of men undergoing urethroplasty) and satisfaction (n = 120, by 48%) were more common feelings posturethroplasty than negativity (n = 33, by 23%).

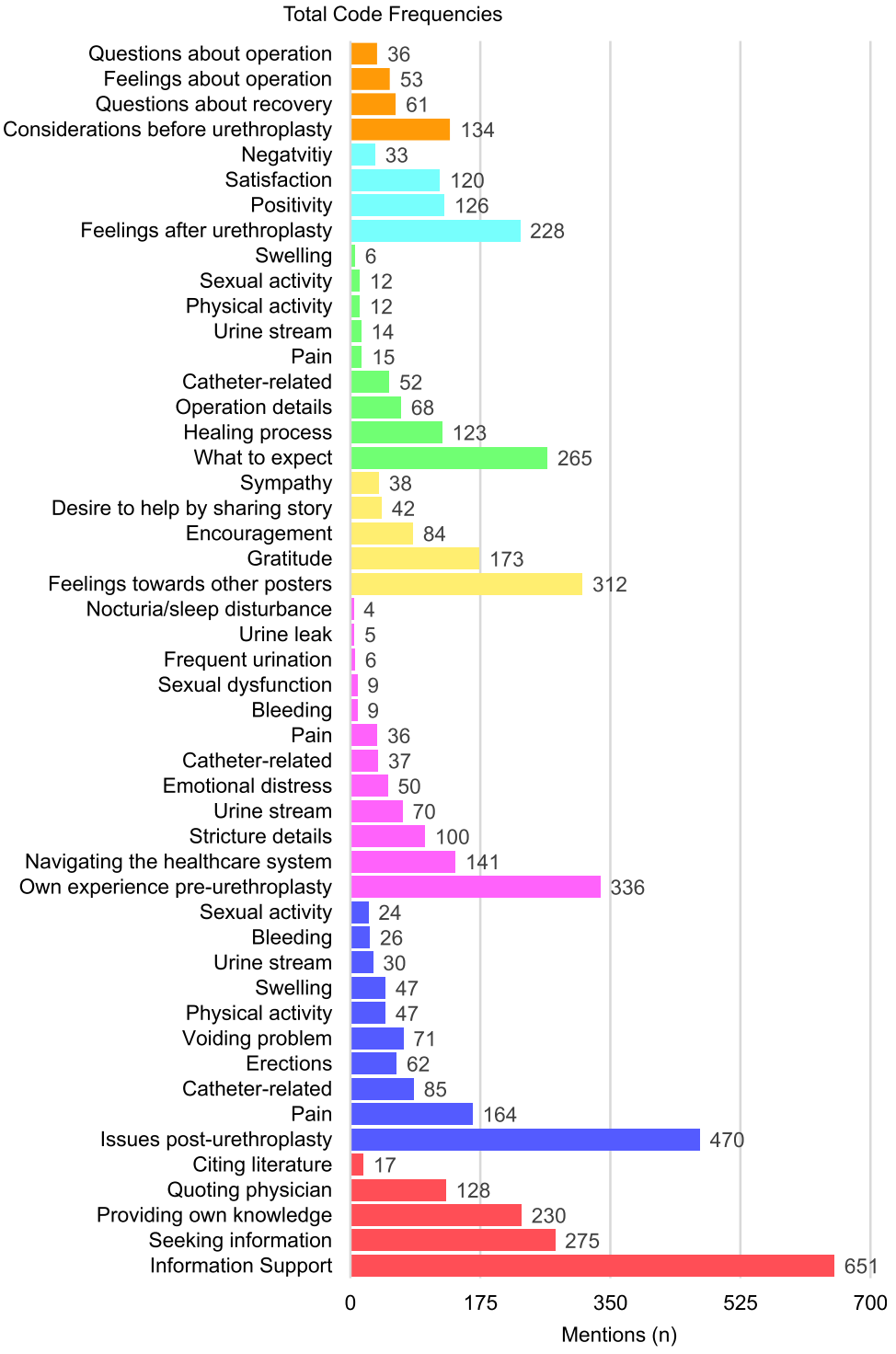

Figure 1. Total code mentions by selective and axial codes. Individual posters may have contributed multiple code mentions. (Colorversion available online.)

Seeking information (n = 275) and providing own knowledge (n = 230) were the most frequent information support categories. The large majority of feelings towards other posters expressed gratitude (n = 173). Patients also expressed positive feelings for having a place to discuss their problems. Encouragement (n = 84) amongst posters was also common.

Code co-occurrences provided more granular insights. For example, issues posturethroplasty had high co-occurrence with feelings after urethroplasty (positivity n = 29, satisfaction n = 26, and negativity n = 8), information support (seeking information n = 64, providing own knowledge n = 47), and what to expect (healing process n = 38). The only postoperative issues that co-occurred with more negative than positive postoperative feelings were urine stream (n = 4), voiding problem (n = 6), and erections (n = 3). However, the sample sizes for these overlapping codes were low. Patients who were seeking information

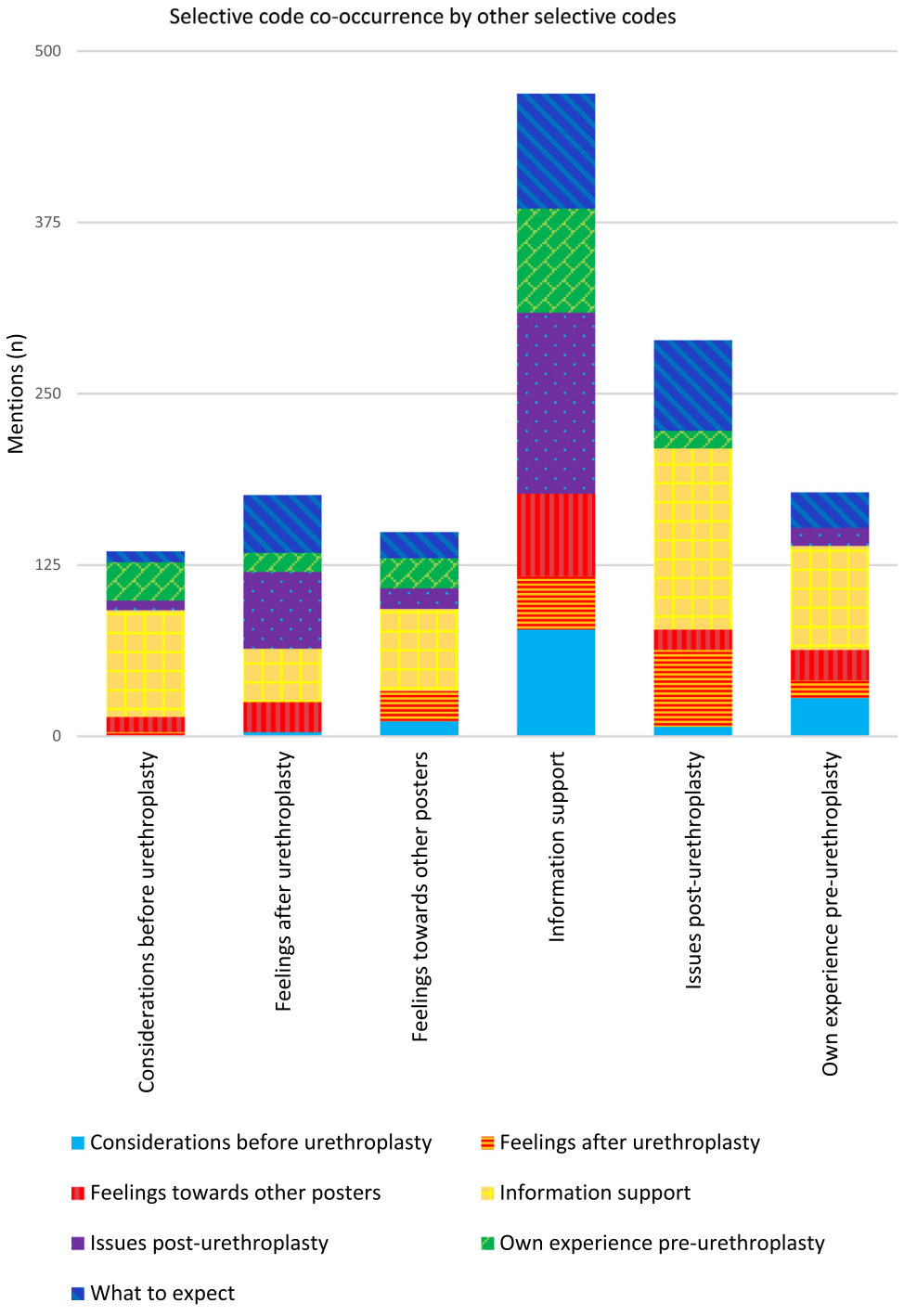

Figure 2. Co-occurrence of selective codes. (Colorversion available online.)

overlapped most often with considerations before urethroplasty (n = 61), issues posturethroplasty (pain n = 16, erections n = 17, catheter-related n = 13), and own experience before urethroplasty (navigating the healthcare system n = 17). Preurethroplasty emotional distress was most commonly applied with other preoperative experiences: navigating the healthcare system (n = 10) and urine stream (n = 9). Figure 2 shows the overlap of selective codes.

Figure 3 illustrates the code co-occurences of information support and pre- and postoperative issues. While the majority of pre-urethroplasty posters inquired about healthcare navigation (n = 17), posturethroplasty issues were clinical in nature, such as pain (n = 16) and erections (n = 17).

DISCUSSION

This qualitative study demonstrates the substantial impact of USD and urethroplasty on quality of life as viewed from the patient's online self-report. Over 500 unique posts were found on the topic of urethroplasty. Two-thirds of the men posting online underwent urethroplasty,

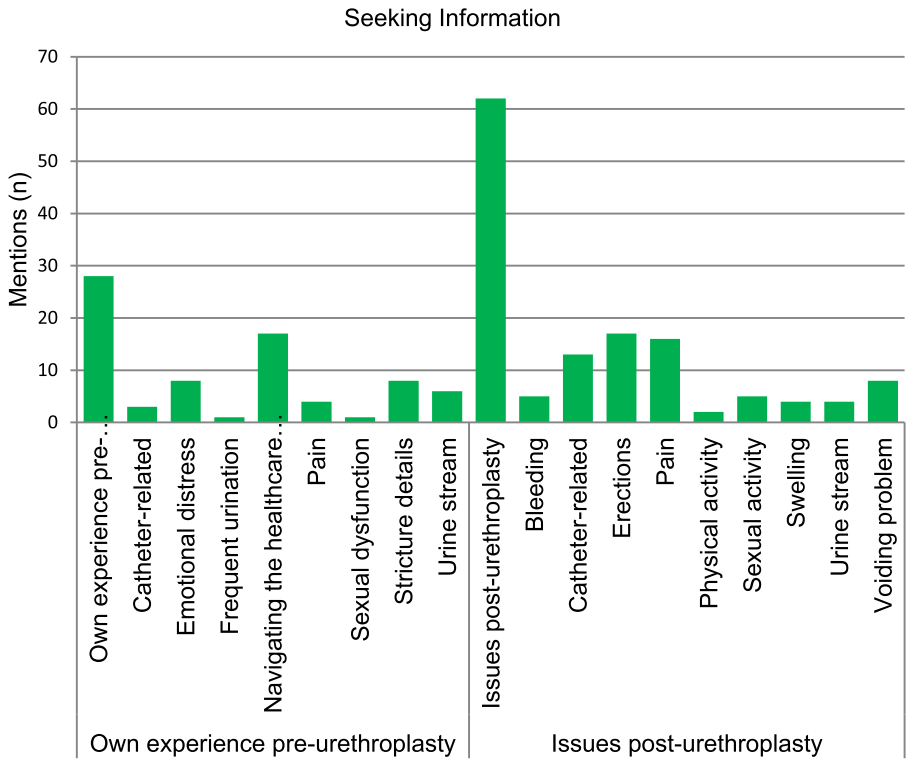

Figure 3. Frequency of posters seeking information by pre- and postoperative issues based on code co-occurrence data. (Colorversion available online.)

almost half of which were by BMG for those who specified. The majority of postoperative patients tended to comment within the first month after surgery, indicating that the forums pertained to issues in the acute phase. Weak urine stream was the most common USD symptom, which has previously been reported as the most frequent presenting symptom for patients undergoing urethroplasty.[5] The majority of men felt positively about urethroplasty. Seeking information support, discussion of issues posturethroplasty, and descriptions of one's own experience preurethroplasty were the most represented reasons for online discussion.

Information support was the most prominent topic. We speculate that some men may not receive necessary education from their physicians, or that patients require additional reassurance from peers. Studies have shown that participation in online social health networks increased medical knowledge and empowered patients.[6] Additionally, engagement with web-based interventions can impact patient decisions such as alcohol abstinence and are being tested for encouraging a heart healthy lifestyle.[9,10] The men with USD in our study often expressed that hearing from other men with similar experiences was helpful and were grateful for the responses. Quality of information in online health forums is generally good, with physicians and laypeople rating only rare instances of extremely poor information.[11] This finding reduces the concern for men to disseminate incorrect or dangerous information. There was large overlap between information support and posturethroplasty issues as demonstrated by code co-occurrence. Patients experiencing complications may have been more likely to search for additional sources of information in order to determine whether their symptoms were typical, how to manage them, and what to expect regarding resolution.

A discussion of posturethroplasty issues were the second most common subject, including postoperative pain, urinary complaints, or issues with erection. Patients can have pain in the perineum and graft site,[12-14] which were the subject of much discussion in our forums. Oral pain typically resolves for 90% of patients within 6 days postoperatively.[14] Our study included men who were recently postoperative, when pain is normal and expected. Such pain may resolve with further follow-up when men may have less motivation to post. Prior reports of postoperative erectile issues indicate new-onset penile curvature, shorter length, and altered sensitivity can occur in the short term.[15,16] In our cohort, men complained most frequently of painful or shorter erections, which have been associated with lower postoperative satisfaction and co-occurred with more negative sentiments in our study.[17] Given the importance of sexual function to patients, it may be beneficial for physicians to counsel accordingly and set appropriate expectations. Postoperative voiding issues were also associated with more negative than positive feelings in our study and prior research.[18]

Navigating the healthcare system was the most prevalent issue before urethroplasty in online forums. This topic accounted for interactions with the health system, including searching for reconstructive urologists and undergoing

prior nonurethroplasty procedures such as urethral dilation and direct vision internal urethrotomy. In an effort to improve provider understanding of patient treatment preferences and as an educational tool for patients, our group previously produced a conjoint analysis related to USD. Conjoint analysis is a tool that ranks patient treatment preference, taking multiple dynamic scenarios into consideration. Such web-based modules may aid providers and patients in navigating the preoperative USD management choices that were often discussed on the online health forums.[19]

Approximately 88% of posturethroplasty feelings in the forums expressed positivity and satisfaction. Both of these sentiments appeared in approximately a 4:1 ratio compared to negativity. Delong and Buckley found that AUASS and QOL scores improved after reconstruction, which also correlated with objective measurements of flow rate.[20] The 2 most important items rated by patients in Breyer et al's study on patient centered outcomes were worry about inability to pee and postmicturition dribbling, with weak urine stream another highly rated concern.[8] The results of our study further confirm the significance of these urinary symptoms to patient QOL and satisfaction. Patients with poor voiding expressed greater negative feelings. Positivity and satisfaction co-occurred frequently with the codes what to expect and healing process, suggesting that men who were commenting about their own urethroplasty experiences may have ultimately had resolution of their condition or symptoms, or had felt enough improvement, to post optimistic comments. Most men were happy with their voiding function postoperatively. One patient underwent end-to-end anastomosis and failed initial catheter removal due to a leak. However, he continued to update his status: "No idea what my rate is, but I must of had this damned my entire life. I have never peed like this, ever... Things are good! Peeing is great, erections seem to be getting better... So far again this surgery is life changing and totally worth it... [I] would do again, flow is amazing."

Our study has limitations. We analyzed a convenient sample of online forums for urethroplasty. Our codes were created based on 10% of the comments, and therefore may not be comprehensive. Some of the codes did not capture certain details (eg, the demographics of posters) or discriminate between more granular subtypes (eg, buccal vs penile pain or erectile pain vs erectile length). Code application is subjective and therefore susceptible to differences between coders. We discussed correct interpretation and application before coming to unanimous decisions in an effort to reduce such disagreement, and practiced coding the same posts for consistency. Furthermore, posters on these forums may not be representative of the general population of men with USD. Our ability to draw conclusions were limited by the patients' level of participation. For example, patients may have posted their experiences or sentiments and then not followed up with changes or updates (eg, pain that resolved, negative feelings that became positive, or satisfaction that didn't last).

CONCLUSION

Men with USD participated in online discussion boards primarily for information support regarding urethroplasty and understanding the expectations of their subsequent recovery. Pain was the most frequent postoperative issue. The majority of men were satisfied with the outcome, with satisfaction and positivity each outnumbering negativity by approximately 4:1. These results provide insight into the most important issues for men with USD considering or recovering from urethroplasty and how physicians may best provide support and education.

SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at https://doi.org/10.1016/j.urology.2019.03.033.

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EDITORIAL COMMENT

Urologists often wonder how patients perceive a surgery they underwent. When a patient follows up in the office, however, clinical concerns and needs of the urologist and the patient often prevent an objective assessment.

In this study, the authors performed an analysis of online forum posts regarding urethroplasty and identified 553 posts from 140 individual writers. Although this is a rather small group of patients compared to the number of urethroplasties performed, even annually, it depicts the current state of information that can be accessed when querying Google for urethroplasty.

The most pressing concern voiced by patients preoperatively was difficulty navigating the healthcare system, specifically finding the appropriate reconstructive urologists, their experience with endoscopic stricture treatments, and their need for emotional support. This raises the question how often stricture patients are appropriately referred to a reconstructive urologists or if they are more heavily relying on information found on the internet to find specialty care.

The most common discussion topic postoperatively was pain. Given that the majority of patients commented within 1 month of the surgery during the healing phase, this would suggest that urologists should set expectations regarding pain more accordingly.

Overall, the vast majority of patients voiced positivity and satisfaction with their surgery. This is most encouraging considering that posts are often used to voice negative concerns and unhappiness, making the trend in positivity even more noteworthy.

In summary, while limited by a small number of patients that posted in internet forums that may not represent the urethroplasty population as a whole, it is likely patients coming for a consultation may have done their own online research beforehand and read this same body of posts. Whereas long-term outcomes such as freedom of recurrence may be most important to the urologist, this study shows that short-term issues such as postoperative pain are of most concern to the patient in the immediate and therefore should be addressed accordingly.

Matthias D. Hofer, Department of Urology, Northwestern University Feinberg School of Medicine, Chicago, IL

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